Patient knowledge in inflammatory bowel disease: the Crohn’s and Colitis Knowledge Score
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In the UK, key professional organizations have joined to provide inflammatory bowel disease (IBD) standards to be delivered by the NHS, highlighting the importance of patient education and support. The Crohn’s and Colitis Knowledge Score (CCKNOW) is a validated multiple-choice questionnaire on the subject of IBD that is able to objectively quantify the level of patient knowledge. The aim of this study was to summarize the findings of the CCKNOW, in particular, the current level of patient knowledge and the implications clinically. Literature search was conducted using Medline, Google Scholar and the Cochrane Library, compiling results of studies using the CCKNOW to date. In the UK, a median score of 10 was achieved by participants with IBD in Leicestershire in 1999. Recent surveys in the Northwest and Pennine Trust achieved median scores of 9 and 7, respectively. Knowledge deficits regarding fertility and pregnancy were found, as seen in 1999. Studies in Canada and Iran achieved median scores of 13 and 4, respectively. Sri Lanka achieved a mean score of 6.86 (range 1–16). Higher CCKNOW scores were associated with the use of adaptive coping strategies. A significant positive link was found between patient knowledge and anxiety levels.

Introduction
In the UK, key professional organizations have collaborated to provide inflammatory bowel disease (IBD) standards to be delivered by the NHS, highlighting the importance of patient education and support [1]. Few literatures exist, however, regarding what patients with IBD understand of their illness. This review aims to summarize the findings of the Crohn’s and Colitis Knowledge Score (CCKNOW), a tool originally developed to assess the effectiveness of education for patients with IBD [2]. It has been used extensively since its development in contexts varying from the assessment of educational tools to quantification of patient understanding and subsequent clinical implications.

Inflammatory bowel disease
IBD describes two conditions, ulcerative colitis (UC) and Crohn’s disease (CD), both of which are chronic inflammatory conditions affecting the gastrointestinal tract. They follow a relapsing and remitting course and diagnosis is usually made in early adult life, meaning high costs for IBD patients and society as a result of extensive laboratory tests, procedures, hospitalization and surgery [3–5]. The incidence of IBD varies considerably across the globe with the highest rates traditionally reported in northern and western Europe as well as North America. Lower rates are found in Africa, South America and Asia, including China [6,7].

The CCKNOW
The CCKNOW is a multiple-choice questionnaire on the subject of IBD developed by Eaden et al. [2]. Originally consisting of 30 questions, factor analysis reduced it to 24 by eliminating questions with a poor ability to discriminate between groups of participants. The 24 questions are divided into five areas: general knowledge (eight), anatomy (four), medications (five), diet (two) and complications (five). Scoring of the questionnaire is one point for each correct answer with no negative marking. It was originally piloted on a random selection of participants with differing IBD knowledge levels; junior doctors (17), nurses (16) and ward clerks (20) and scores were found to differ significantly between the groups (median 22, 16 and 5, respectively, \( P < 0.0001 \)). The validated CCKNOW test was then completed by 354 UC and CD patients on the Leicestershire IBD database reporting a median score of 10 (95% confidence interval 9–10) [2]. Results showed no significant difference in score...
between patients with UC or CD. Patients who were members of the National Association of Crohn’s and Colitis (NACC), however, achieved statistically significantly higher scores than nonmembers. Furthermore, recognized statistical tests show the CCKNOW to be a valid, reliable and readable questionnaire [2].

Besides the CCKNOW, the only other published questionnaire for IBD was developed by Jones et al. [8], entitled the Knowledge Questionnaire. Yet, apart from the sole original study, limited evidence exists documenting its use. In comparison, the CCKNOW has been embraced internationally, fuelling research into educational tools and measures of patient and staff IBD understanding.

Use of the CCKNOW

The greatest application of the CCKNOW to date has been the quantification of patient’s disease understanding both inside and outside of the UK.

Within the UK, national recommendations exist to target IBD patient education and support, for example ensuring good quality predischarge information on medication, self-care and follow-up [1,9]. Combined with the wealth of information already available from patient groups, books and the worldwide web, it would be reasonable to expect that general knowledge among IBD patients should be improving [10–12]. The most recent survey was based across eight different hospital trusts in the northwest of England [13]. From a total of 127 completed questionnaires, the median CCKNOW score was 9. In 2011, the Pennine Acute Hospitals NHS Trust in Manchester asked patients to complete a total of 236 CCKNOW questionnaires [14]. Here the median score was 7, with weaknesses highlighted in surgical knowledge, fertility and implications regarding pregnancy. When compared with the original CCKNOW development study, the scores imply that knowledge of IBD may be no better in the UK than when surveyed in 1999 where the median score was 10. The original study also found similar deficiencies in knowledge regarding fertility and implications for pregnancy. These results suggest that the national recommendations and additional resources have less effect.

In terms of NHS healthcare delivery, the effect of increased time pressures and limited resources may be the most obvious candidate for the apparent failure of improvement [15–17]. In a recent survey of IBD patients, at least one in 10 reported suboptimal aspects of discharge information about drug side effects, warning signs to watch for or how to manage their condition once home [9]. More conventional teaching strategies led by a nurse, including patient classes or group-based discussions, have shown significant improvements in knowledge when assessed with the CCKNOW [18,19]. Why these techniques are not being implemented may be because of the previously mentioned pressures within the healthcare system. Alongside this, although the internet is a powerful tool, patient’s access to inaccurate information may be damaging [10–12]. The CCKNOW itself has been used to show that significant improvements can be made after short periods of time with interactive multimedia applications and internet-based training tools [20,21]. Again this potential is not being realized and professionals may not be effectively directing patients to reliable and accurate health websites [22]. The subjects of fertility and implications for pregnancy are particular areas of deficit in the original and more recent studies. Specifically, very few patients understood that in men, sulphasalazine can cause reversible oligospermia, and women with active CD may find it difficult to conceive. This may reflect the conflicting clinical evidence available in these areas or hesitancy in broaching such sensitive topics [23]. Although it is easy to point at the healthcare systems’ potential faults, patients’ own attitudes toward what they should know about their disease may also be changing with time; however, few literatures exist in this area. It may also be argued that because of the medical and technological advances since 1999, revalidation of the questionnaire itself may be required.

In Canada, 47 IBD patients achieved a median score of 13 in a study by Paterson et al. [24], the highest results published to date. With the incidence of IBD beginning to stabilize in high incidence areas such as northern Europe and North America, but continuing to rise in traditionally lower incidence areas including Asia and other parts of the developing world, there is growing interest in what patients in these areas understand about their disease [25]. In the first survey of its kind, 100 patients in Iran completed a Farsi-translated version of the CCKNOW with a median score of 4, significantly lower than that seen in the developed countries [26]. In addition, 184 patients in Sri Lanka have since completed a Sinhala-translated questionnaire with a mean score of 6.86 (range 1–16). No median score was provided by this study [27]. Both studies found a common deficit in knowledge regarding the risk of IBD complications. On the basis of these results, generally speaking, lower CCKNOW scores are achieved in the developing countries in comparison with western countries.

Why such differences exist between developing countries and the West is unknown, but may be attributed to lower incidence and prevalence rates, poorer quality healthcare services and limited access to web-based and published material in native languages [28]. Interestingly, unemploy ed or lesser educated patients in the Sri Lankan study achieved significantly poorer CCKNOW scores than their employed or educated counterparts, alluding toward the effects that economic and social differences can exert within a country [27]. It does not seem unreasonable to suggest that such interpretation could be extrapolated to an international level to help explain
differences between developed and still developing countries. How successfully the CCKNOW was translated into Farsi or Sinhala may have also contributed to their CCKNOW scores. For this reason there may be a case for revalidation of the translated versions of the CCKNOW, although no language difficulties were reported by either study.

It must be stated that these CCKNOW score comparisons do not take into account many other variables that exist between the study populations. Although this review has presented all of the available data, it is somewhat limited by the detail of the results produced. Confidence intervals and interquartile ranges were generally unavailable.

Clinical implications

When looking at other chronic conditions besides IBD, educational interventions have successfully been shown to improve compliance in patients with type-1 diabetes mellitus, and to reduce hospitalizations in patients suffering from asthma [29,30]. As mentioned previously, validated educational tools exist to improve patients’ understanding of IBD but the real question is whether increased knowledge translates into improved disease outcomes and quality of life.

Moradkhani et al. [31] hypothesized that individuals with greater IBD knowledge would exhibit improved coping strategies and then tested this theory by using the CCKNOW and the ‘Brief COPE’ questionnaire. The Brief COPE included 28 items, measuring 14 different recognized coping reactions. Some of these reactions are known to be adaptive, whereas others are more detrimental to the coping process. The Brief COPE therefore provides researchers a way to assess important coping responses quickly and reliably [32]. A significant positive association was found between IBD knowledge and active coping scores, instrumental support scores, planning scores and emotional support scores. Greater IBD knowledge therefore seems to be associated with the utilization of more adaptive coping strategies in IBD patients. This may be advantageous as it has been shown that IBD patients have significantly poorer psychological health and view their general health more negatively than nonsufferers [33]. It should be noted that this study used the 30-item CCKNOW questionnaire including questions thought to be poorer at discriminating between groups of participants than the more widely used 24-item questionnaire.

Conversely, a significant link has been found between increased patient knowledge and anxiety levels. The CCKNOW was completed alongside a short IBD questionnaire (SIBDQ) to assess disease-related quality of life [34]. Hospital Anxiety and Depression Scores were used to assess anxiety (HADS-A) and depression (HADS-D). The results echo those by Larsson et al. [35] who reported that patients with high anxiety levels appeared not to experience any benefits in terms of reduced anxiety after participating in an education programme. Educational tools may therefore be ineffective in combating anxiety in patients with IBD.

Widespread use of the CCKNOW has highlighted a common deficit in knowledge regarding the complications of IBD, particularly in the developing countries [26,27]. In theory, better educated patients should be more likely to manage their disease appropriately, for example by attending colonoscopies or complying with medication and reduce their risk of complications such as colorectal cancer. Whether patient knowledge factored into an increased risk of UC patients developing colorectal cancer has been asked by a retrospective case–control study [36]. Interestingly, the results were not as hypothesized; the study found no significant difference in the CCKNOW scores between case and control populations.

Drawbacks of the CCKNOW

The interpretation of the scores produced by the CCKNOW questionnaire remains its biggest challenge. Most studies have struggled to provide valuable discussion after using the questionnaire and no study so far has attempted to answer the difficult question of what an appropriate level of patient knowledge actually is. Instead, basic comparisons have been made between scores from their own study populations and other studies, resulting in an overall approximation of ‘poor’ or ‘average’ patient knowledge to base their conclusion. Although comparisons may be useful in highlighting weaker study populations, they are of no use individually where no thresholds exist. This is a huge disappointment as much effort has gone into conducting these studies. In the development of the CCKNOW, Eaden et al. [2] did provide a clue as to score interpretation by presenting scores achieved by junior doctors, staff nurses and ward clerks, which may be used as a comparative guide. However, owing to limited distribution, it has seldom been used. What then should be expected of an IBD patient? In the era of self-management, one may expect a score above that of a nonspecialist staff nurse to be ‘good’, above a ward clerk to be ‘average’ and below that ‘poor’. If this was the case, then all of the studies included in this article would fit into the ‘average’ category apart from that carried out in Iran, which would be deemed ‘poor’. This interpretation makes the CCKNOW more useful to researchers but shows little differentiation between the results produced by the majority.

Very few practical issues with the use of the CCKNOW have been reported. Elkjaer et al. [21] noted that half of the patients in their study felt that questions were too difficult. The study also questioned the relevance of the two questions relating to diet as they concern lactose intolerance and elemental feeds, topics which they felt...
did not cover patients' dietary concerns. Subasinghe and colleagues felt that as colonoscopy is widely used in the follow-up of patients with IBD, a question regarding this may add value to the questionnaire (D. Samarasekera, personal communication, 17 April 2013).

The future
As individual patients may deviate somewhat from their populations’ median score, this may make the CCKNOW more helpful when trying to assess what an individual understands of their condition relative to other IBD patients. Regular use in patients awaiting outpatient appointments, for example, may highlight to the clinician patients with particularly poor knowledge. It will also help to identify topics that should be given extra attention. These patients could then be targeted for increased access to educational tools or extra appointments with a specialist nurse.

The CCKNOW may hopefully encourage the development of newer more precise questionnaires aimed specifically at patients. One such example is the ‘Crohn’s and Colitis Pregnancy Knowledge Score’, CCPKnow, a tool developed by Selinger et al. [37] to test patient’s knowledge of IBD and its treatment before and during pregnancy. The CCPKnow has been administered to 145 women with IBD and nearly half had poor knowledge, identifying a pressing need for better education.

Conclusion
The CCKNOW has revealed that in the UK, the current level of patient knowledge of their IBD may be no better than in 1999. This has specific consequences as regards to standards of IBD care, which have now become an integral part of the UK national audits [1,9]. It is apparent that the subjects of fertility and implications for pregnancy may be particular areas of deficit. The CCKNOW has helped to confirm that effective educational tools exist, and that the UK active membership of the NACC is associated with increased disease understanding. Application in Iran and Sri Lanka exposes further knowledge deficits that may exist in particular areas of deficit. The CCKNOW has helped to identify topics that should be given extra attention. These patients could then be targeted for increased access to educational tools or extra appointments with a specialist nurse.

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Significant research is required into the clinical benefits of attaining greater disease knowledge before any evidence-based recommendations for widespread use can be made. What is clear is that the use of validated assessment tools such as the CCKNOW have made this type of research more feasible.

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Conflicts of interest
There are no conflicts of interest.

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